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Title

A collaborative approach between clinicians and researchers in dementia care to improve clinical effectiveness and priorities for research through audit.

INTRODUCTION

With an aging population increased demands on the systems that support them have arisen (Organisation for Economic Co-operation and Development 2017). Understanding this population's health and social care needs is crucial to enable the future provision of appropriate cost-effective care. Outcome measures may be one way to achieve this. Outcome measures record the change in health status as a result of health care provision or interventions undertaken (Murtagh et al 2014). Using patient-centred outcome measures in routine care can promote person-centred care by facilitating assessment and detection of concerns important to the person. This understanding can enhance care processes and in turn improve outcomes (Greenhalgh 2009; Ellis-Smith et al 2018; Etkind et al, 2015). However, many outcome measures have been developed in oncology or palliative care settings (Masso et al 2015; Abernethy et al 2005). Evidence is required on adoption in wider clinical settings and populations to inform use in routine care. IPOS-Dem (Integrated Palliative care Outcome Scale-Dementia) is a proxy-completed outcome measure for people with dementia and multi-morbidity living in care homes. IPOS-Dem was developed from the established and widely used Palliative care Outcome Scale family of measures https://pos-pal.org/maix/ipos-dem.php.

An intervention's adoption into practice requires more than evidence emerging from research. Kitson et al (1998) highlights two further sources of evidence - clinical experience and patient preferences. Traditionally evidence across these three domains has emerged from audit, service evaluation and research. These activities are usually undertaken separately. Organisations either initiate new knowledge (academic institutions) or measure their practice against such emergent knowledge (clinical organisations). Integration, rather than separation of these activities, may enable mobilisation of knowledge into practice to enhance evidence-based cost-effective care. It provided the opportunity to develop a reference point for best practice. This collaborative baseline audit sought to understand the use of outcome measures to enhance comprehensive assessment of individuals with dementia and multi-morbidities in routine care across dementia care settings, and explore using IPOS-Dem across care settings.

AIM

To understand how best to implement outcome measures into services for people with dementia across clinical settings.

OBJECTIVES

The audit had three objectives:

- To identify processes of implementing outcome measures in routine care and explore staff perceptions
- To analyse fully pseudonymised audit data for quality and completeness
- To feedback to clinical services about the outcomes of care to inform care provision

METHODS

Audit set-up:

Researchers in the academic institution developed the POS family of measures, supporting their wide use in palliative care clinical practice and research. Clinical services sought advice from the researchers on implementing IPOS-Dem into routine clinical care of people with dementia to improve the quality of care provided and to evidence its outcome. Discussions

between the researchers and the clinical services led to a collaborative audit as a way to support implementation of IPOS-Dem across clinical services and explore feasibility of using outcome measures in routine care.

Subsequently when other clinical services contacted the researchers and/or the authors for support to implement IPOS-Dem into routine practice for people with dementia, they were informed about the audit and invited to take part. This resulted in eleven clinical services in England expressing interest in collaborating with the academic institute. Initial visits to each of the clinical services were made by the authors [JK/CES] to explain the audit and confirm continued interest in collaboration. Once agreed, the clinical services and researchers worked together to agree the baseline standard for a 6-month audit. A Data Sharing Agreement between each of the clinical governance bodies responsible for the clinical audit and the academic institution detailed the roles and responsibilities of all taking part in the audit including when and how information could be shared. This audit activity was considered by the HRA to not constitute research and did not require NHS ethical approval https://researchsupport.admin.ox.ac.uk/sites/default/files/researchsupport/documents/media/defining-research.pdf. The Data Sharing Agreements allowed for the clinical services to share anonymous audit data with the academic institution. Data Sharing Agreement included a statement that anonymous audit data could be used for subsequent research and teaching purposes. Subsequent ethical approval was received from King's College London ethics committee (REMAS) for secondary data analysis of the audit data (REC number: LRS-17/18-7969). The secondary analysis of the data is contributing to knowledge on e.g. symptom distress and change over time, and benchmarking against the audit standard.

Audit process:

The process commenced with 'face-to-face' training by CES and JK with the clinical service leader/s on the outcome measures to be implemented, using for example case scenarios to explain using the measures in routine care. The clinical leads then trained the staff within their respective organisations to implement the measures using team meetings and role modelling, and tailoring implementation to the respective clinical setting and population. JK/CES provided advice and support throughout the audit process. See Box 1 for the final agreed baseline audit standard.

Standard: **Outcome measures baseline audit standard**

Care Group:
People with dementia

Standard Statement:
Care providers will complete outcome measures to learn about and develop the palliative care/end of life care they provide.

Structure:
1. Demographic data, IPOS-Dem (including four additional questions for staff to complete), Phase of illness, Australian Modified Karnofsky Performance Scale and Functional Assessment Staging for each person with dementia fully completed at the correct time intervals.
2. Completed documentation will be available for electronic analysis.
3. Time is available for each participating service to reflect on the analysis of the outcome measures every three months.

Process:
1.1 The participating services will complete the demographic data, IPOS-Dem (including four staff questions), Phase of illness, Australian Modified Karnofsky Performance Scale and Functional Assessment Staging for each person with dementia in their care.

1.2 At each change of Phase the demographic details will be reviewed and all measures repeated. If no change of Phase this must be repeated at a minimum every month.

1.3 Each person will have a unique identifiable audit number which will be added to any completed paperwork.

1.4 Service providers will hold the record of this identifiable audit number and what measures have been completed and when.

2.1 Prior to commencing this audit a data sharing agreement to be in place between each participating service and the academic institution.

2.2 There is a ready supply available of photocopied, correctly coded outcome measures.

2.3 Each of the participating services will have a unique identifiable number as well.

2.4 The participating services will ensure anonymised hard copies (photocopied) of each completed measure are forwarded securely to the academic institute at three monthly intervals.

2.5 The academic institute will analyse the results

3.1 JK and CES, on behalf of the academic institute, will meet with the service provider every three months to give them feedback on completed measures as a reflective process

3.2 Following the reflective sessions, the service providers will make changes, organise training, give support and celebrate good feedback.

3.3 Evidence of improvements in the quality of palliative care/end of life care provision arising from this process will be shared with staff, external providers and commissioners.

Outcome:
1. The completion of IPOS-Dem (and four staff questions), Phase of illness, Australian Modified Karnofsky Performance Scale and Functional Assessment Staging in routine practice in terms of data quality and completeness will be better understood. Staff will reflect on and learn from the outcome measures completed in order to develop their provision of palliative care/end of life care.
2. Staff will use the feedback from their completion of the outcome measures into routine practice to improve the quality of palliative care/end of life care they provide and be able to evidence that they have done this.
3. Implementation sites follow NICE dementia guidance to ensure comprehensive assessment of symptoms and concerns in people with dementia presenting with agitation.
4. Staff gain confidence and skills in palliative care/end of life care.
5. Findings will be disseminated at a local, national and international level via publications and presentations.

Box 1: Baseline audit standard

The clinical services assessed patient eligibility (e.g. a formal diagnosis of dementia) and implemented the outcome measures to support care processes of assessment and review, using the measures at baseline and repeated monthly and at points of clinical change, e.g. increasing distress. The measures comprised:

1. Integrated Palliative Care Outcome Scale for Dementia (IPOS-Dem) (Ellis-Smith et al 2018)
2. Palliative Care Phase of Illness (Masso et al 2015)
3. Australia-modified Karnofsky Performance Scale (AKPS) (Abernethy et al 2005)
4. Functional Assessment Staging (FAST) (Reisberg B. 1988)

Box 2 provides additional information on each of these measures.

1. Integrated Palliative Care Outcome Scale for Dementia (IPOS-Dem)
This enables a comprehensive and holistic assessment of the symptoms and concerns of people with dementia when they are unable to vocalise these. It can be completed by staff and or family members. Each item is scored from 'not being a problem at all' to 'overwhelming' or 'always'.

2. Palliative Care Phase of Illness Phase of illness
This helps staff focus on the phase of a person's illness by identifying if they are stable, unstable, deteriorating or dying.

- Stable means that the person's problems and symptoms are adequately controlled by an established plan of care. Interventions to maintain symptom control are planned, the family/carer situation is stable and ne new issues are apparent.
- Unstable means an urgent change in the plan of care or emergency treatment is required because the person experiences a new problem that was not anticipated in the existing plan of care
- Deteriorating means the care plan is address needs but requires periodic review as the person's function is declining.
- Dying means that death is anticipated within days.

3. Australia-modified Karnofsky Performance Scale (AKPS)
This measures the functional status of a person. Categories decrease from 100% which means the person is 'normal with no complaints' and 'no evidence of disease' through to 0% when the person is 'dead'.

4. Functional Assessment Staging (FAST)
This identifies dementia severity using a scale that ranges from 1 which represents normal aging with no deficits to 7f which is severe dementia where the person can no longer hold their head up.

Box 2: Detail of what each of the four measures recorded

Clinical staff collected data on a hard-copy proforma or on an Excel spreadsheet. De-identified anonymous data was shared with the researchers. Descriptive data analysis was undertaken and the proportion of completed and missing data overtime. Data was imported into a relational database [MySQL -https://www.mysql.com/] and analysed using the PHP programming language. Two feedback sessions to each of the clinical services were planned to improve the care they provided and evidence this. The initial session (at three-months) intended to support the audit leads and answer questions regarding the audit process. The second session at six-months, with all staff involved in the audit explored their experiences of using the measures in routine practice. Handwritten notes were taken with verbal permission gained to use this in data reporting. Finally, a summary of the results for each service and incorporating staff feedback, was shared with each clinical service and confirmation on accuracy/completeness obtained.

RESULTS

Of the 11 clinical services involved, nine completed the audit within the 6-month timeframe. The remaining two services experienced administrative delays in internal approvals for the Data Sharing Agreement. The nine clinical services comprised:

- **Community services**
  - Nursing home [n=2]
  - Residential home [n=2]
  - Community service supporting people with dementia [n=1]
  - Specialist palliative care dementia service [n=1]
  - Community early diagnosis support service [n=1]

- **In-patient services**
  - Acute mental health inpatient unit [n=1]
  - Acute hospital team – proactively preventing admissions/re-admissions into hospital/supporting those admitted [n=1]

People with dementia

Anonymised audit data was submitted for 225 people with dementia. Of these 63% (n=142) were female. Their mean age was 82 years. Whilst the majority (81%) were White British there was extensive ethnic diversity in the remaining 19%. Alzheimer's disease formed the main diagnosis 31% (n=69) followed by mixed 28% (n=62); vascular 24% (n=54); and, other 9% (n=21). Nineteen people (8%) had this data missing.

The number of people with dementia from each clinical setting, varied at the outset (median 23; range 8-59) and decreased over time. The highest recruiting area was the community early diagnosis support service n=59. While the lowest recruiting clinical services were both inpatient units (acute hospital team recruited n=8 at first assessment, and n=1 follow-up for two-timepoints); and acute mental health unit, n=23 at first assessment, with n=1 follow-up for four-timepoints).

Outcome measures at first assessment

IPOS-Dem

The clinical services reported that where possible information was sought from the person themselves, with use of proxies, for people lacking mental capacity to self-report. Of note was that skin breakdown was the only symptom with no missing data. Much of the missing data was in relation to non-physical symptoms such as 'lost interest'. Details of symptom prevalence and severity are summarised in Table 1.

Phase of Illness

Most people with dementia were stable n=155 (69%) with the remaining reported as either unstable (n=21;9%), deteriorating (n=44;20%) or dying (n=5;2%). No data was missing.

Table 1: Prevalence and severity of IPOS-Dem symptoms at first assessment (n=225)

Symptom (n)	Prevalence and Severity over the past week n (valid %)				
	Not at all	**Slightly**	**Moderately**	**Severely**	**Over-whelmingly**
Pain (215)	104 (48)	45(21)	47 (22)	17 (8)	2 (1)
Shortness of breath (223)	161 (72)	29 (13)	22 (10)	10 (5)	1 (0)
Weakness (217)	90 (41)	45 (21)	50 (23)	22 (10)	10 (5)
Nausea (212)	190 (90)	16 (8)	4 (2)	1 (0)	1 (0)
Vomiting (223)	212 (95)	8 (4)	2 (1)	1 (0)	0 (0)
Poor appetite (222)	112 (50)	57 (26)	30 (14)	14 (6)	9 (4)
Constipation (221)	158 (71.5)	34 (15)	24 (11)	4 (2)	1 (0.5)
Dental problems (220)	183 (83)	14 (6)	17 (8)	4 (2)	2 (1)
Sore or dry mouth (218)	178 (82)	23 (10.5)	10 (4.5)	3 (1)	4 (2)
Drowsiness (222)	107 (48)	42 (19)	47 (21.2)	23 (10.4)	3 (1.4)
Poor mobility (224)	73 (33)	41 (18)	45 (20)	37 (16.5)	28 (12.5)
Swallowing problems (224)	171 (76)	24 (11)	16 (7)	6 (3)	7 (3)
Skin breakdown (225)	146 (65)	45 (20)	21 (9.3)	10 (4.4)	3 (1.3)
Problems communicating (223)	98 (44)	33 (15)	39 (17)	40 (18)	13 (6)
Sleeping problems (221)	134 (61)	43 (19)	30 (14)	11 (5)	3 (1)
Diarrhoea (220)	187 (85)	20 (9)	9 (4)	2 (1)	2 (1)
Hallucinations (204)	137 (67)	30 (15)	20 (10)	9 (4)	8 (4)
Agitation (223)	79 (35)	69 (31)	46 (21)	19 (9)	10 (4)
Wandering (223)	175 (78.5)	20 (9)	21 (9.4)	6 (2.7)	1 (0.4)
Symptom (n)	**Not at all**	**Occasio nally**	**Sometimes**	**Most of the time**	**Always**
Feeling anxious (204)	63 (31)	61 (30)	47 (23)	24 (12)	9 (4)
Family anxious (218)	73 (34)	46 (21)	44 (20)	42 (19)	13 (6)
Felt depressed (199)	108 (54)	46 (23)	25 (13)	13 (6.5)	7 (3.5)
Lost interest in things would enjoy (193)	67 (35)	32 (16.5)	40 (21)	32 (16.5)	22 (11)
Symptom (n)	**Always**	**Most of the time**	**Sometimes**	**Occasio nally**	**Not at all**
Felt at peace (205)	45 (22)	91 (44)	31 (15)	24 (12)	14 (7)
Interacting positively with others (220)	69 (31)	55 (25)	43 (20)	28 (13)	25 (11)
Able to enjoy activities (215)	57 (26.5)	36 (16.7)	47 (22)	34 (15.8)	41 (19)
Family had information as wanted (200)	122 (61)	51 (25.5)	13 (6.5)	8 (4)	6 (3)

Symptom (n)	Problems addressed /no problems	Problems mostly addressed	Problems partly addressed	Problems hardly addressed	Problems not addressed
Practical problems addressed (212)	121 (57)	51 (24)	32 (15)	4 (2)	4 (2)

AKPS

Most people with dementia (n=88;39%) functioned at above 50% (able to care for most needs but requires occasional assistance) with n=55 (25%) functioning at 40% or below (in bed more than 50% of the time). The remaining people with dementia n=81 (36%) were recorded as functioning at 50% (considerable assistance and frequent medical care required). Data was missing from n=1. See Chart 1 for further detail.

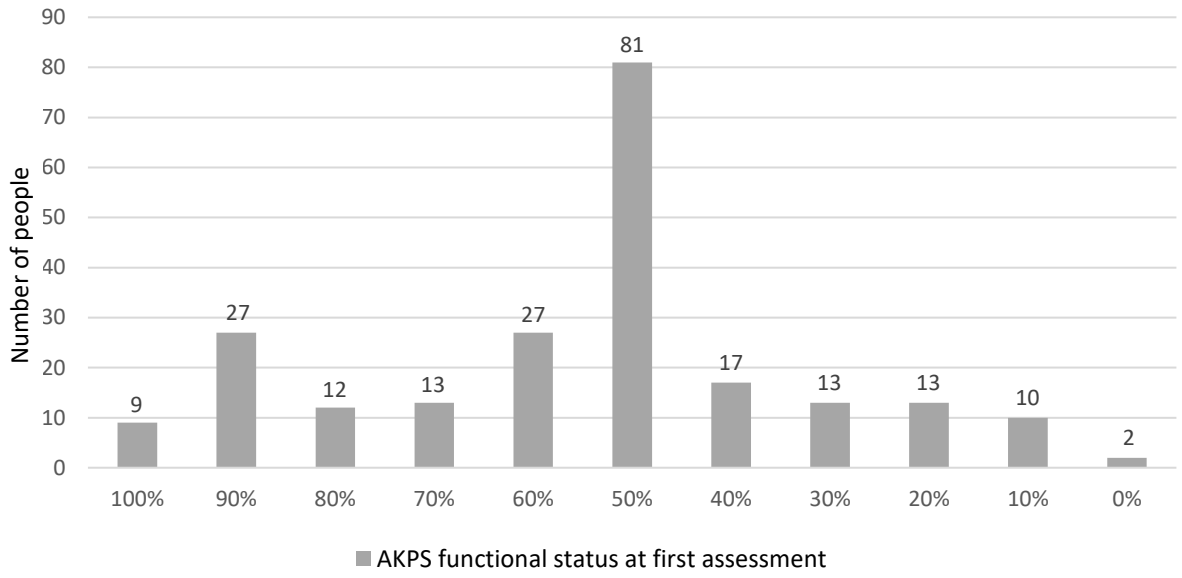
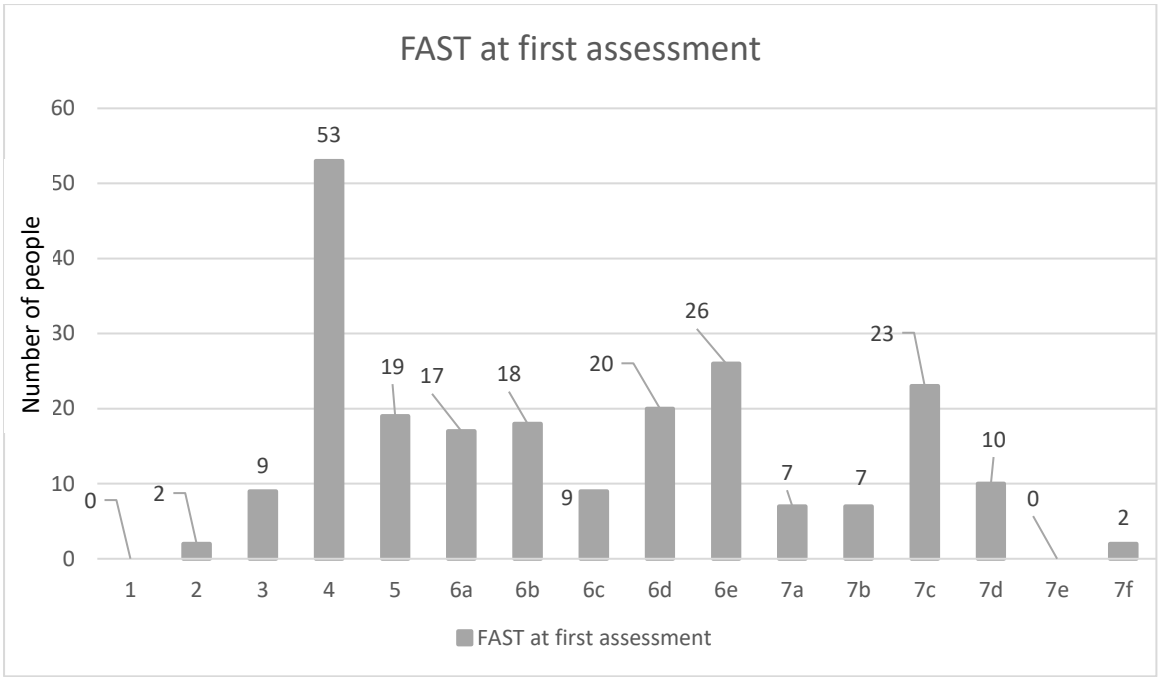


Chart 1: Australia-modified Karnofsky Performance Scale (AKPS) at first assessment (n=224)

FAST

The most and least common stages were moderately severe dementia (n=90;41%) and cognitive impairment (n=11;5%) respectively. Fifty-three (24%) people had mild dementia, n=19 (8%) moderate dementia with the remainder n=49 (22%) documented as having severe dementia. Data was missing from n=3. See Chart 2 for further detail.



Code	Description
1	Normal ageing
2	Possible mild cognitive impairment
3	Mild cognitive impairment
4	Mild dementia
5	Moderate dementia
6	Moderately sever dementia
7	Severe dementia

Chart 2: Functional Assessment Staging (FAST) at first assessment (n=222)

The experience of using outcome measures in routine practice

The audit was positively received by all services. Each clinical service introduced and implemented the outcome measures in a way tailored to their context. The clinical services reported that completion of the respective measures as a paper version was preferred. It was more portable and could be taken to the person for completion. A portable tablet was identified as a potentially acceptable alternative. Every clinical service chose to complete the measures for each person who met the criteria within their care. However, clinical services' data sharing with the researchers adhered to local clinical governance processes, leading to variation in the completeness of the anonymous data received.

Benefits to the use of outcome measures included:

- promoting a comprehensive assessment
- improved team communication
- Health Care Assistants reported feeling included, valued and inspired
- the identification of symptoms/problems and requirement to address, e.g. seeking GP advice

The IPOS-Dem:

- provided a way for family members and the person with dementia to contribute to the assessment process by completing the measure/or contributing to
- facilitated awareness of problems by care staff and family members not previously identified
- people with dementia enjoyed the opportunity provided to discuss problems/concerns/care/treatment

Phase of Illness:

- helped initiate discussion around a change in condition and enabled proactive management of the change

The format of the initial feedback sessions to the clinical services varied from 'face to face' visits to phone and email discussion. It provided the opportunity for clinical leads to ask questions regarding the audit and discuss initial preliminary feedback. This enabled the outcome measures to be completed, and adjusted to suit each context. The audit then captured this local tailoring. For example, one clinical service noted that completing the IPOS-Dem resulted in change, but needed a process to report this. Several clinical leads reported completing the measures monthly not when a person's condition changed and wanted confirmation that this was acceptable. The final feedback was a 'face to face' visit to each of the clinical services presenting analysis on their respective submitted data. The data presented stimulated discussion both on the complexity of the patients they provided care for, and the outcomes from the care delivered.

Where challenges were identified in the feedback session to completing the measures, solutions were found by the clinical services and in collaboration with the authors. For example, completing the measures needed to fit with usual processes of care. All clinical services had continued to complete monthly reviews as aligned to care practices. Some staff reported a lack of knowledge about how to assess symptoms e.g. depression highlighting a training need. A plan was made to enable this training need to be met. Finally measures needed to fit the local context. In some clinical services information recorded in the outcome measures duplicated with information already recorded in existing assessment documents. This iterated the requirement for implementation of measure to be tailored to the local context and integrated within existing care processes.

IMPLICATIONS FOR PRACTICE AND/OR FUTURE RESEARCH

This audit demonstrated the feasibility and acceptability of implementing outcome measures in routine care across settings for people with dementia. Collaboration from the outset, amongst all professionals involved with the audit, led to mutual engagement and learning. The summary feedback on completion of the audit was positively received by all clinical services as it enabled them to identify and learn from collective trends and see the value in using outcome measures in routine care. This has been highlighted previously by others (Greenhalgh and Meadows 1999).

We have demonstrated the benefit from a collaboration between researchers and numerous clinical settings to share learning from the implementation of outcome measures into clinical practice to improve clinical practice and inform future research. Given this finding, formal collaborations between researchers and clinicians should be encouraged, such as the NIHR Applied Research Collaborative and the NIHR ENRICH project for care homes (Lockett et al 2014; National Institute for Health Research 2018).

Findings from the IPOS-Dem audit indicates the breadth of symptoms/concerns experienced by people with dementia highlighting the importance of undertaking comprehensive assessments in practice. Areas with the highest levels of missing data, e.g. 'lost interest' perhaps indicate the challenge of assessing subjective areas. Areas of overwhelming severity e.g. 'enjoying activities' highlight unmet needs of people with dementia (Table 1) these also represent areas of potential interest for future research. In both practice and research, the findings raise concern as most people with dementia, at baseline, were stable and functioning at above 50%.

CONCLUSIONS

Collaboration across clinical and academic organisations offers huge potential for mobilisation of knowledge into clinical practice and ensuring that clinical experience contributes to the generation of new knowledge. The audit enabled increased understanding of the realistic implementation of such measures into practice.

ACKNOWLEDGEMENTS

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